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The role of seniors in the support and social integration of older adults with cognitive impairment

Rola seniorów we wspieraniu i integracji społecznej osób starszych z zaburzeniami poznawczymi

Abstract

Aim. The purpose of the article is to show the role of seniors (especially those in the first phase of old age) in the support and social integration of peers with cognitive disorders. The paper consists of two parts. In the first part, the issue of age diversity of people over 60 and cognitive disorders in the context of demographic aging of Poles is discussed.

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The second part presents the results of an empirical study conducted among seniors supporting elderly people with cognitive disorders, which aims to obtain information on the motivation, scope, and frequency of support provided, and the sense of helping competence of seniors supporting elderly people with cognitive disorders.

Methods and materials. The first part of the article was based on theoretical analysis of scientific publications in the field of social gerontology. The research part was based on qualitative research analysis using the individual in-depth interview (IDI) technique.

Results and conclusion. The widespread process of the aging of the population and the increase in the number of elderly people with cognitive disorders means that providing them with adequate activation and care support is becoming one of the main challenges for Polish social policy. Also related to the process of aging is the issue of providing appropriate forms of activation for seniors (especially in the initial phase of aging). Analyzing the scientific literature in the field of social gerontology, as well as our own research, we come to the conclusion that it is necessary to take measures to encourage seniors to support and activate their peers with cognitive disorders by conducting informational, educational activities and free training courses to increase the knowledge and competence of seniors supporting the elderly.

Keywords: old age, age diversity of the elderly, cognitive disorders, social support, senior support giver.

Abstrakt

Cel. Celem artykułu jest ukazanie roli seniorów (zwłaszcza w pierwszej fazie starości) we wspieraniu i integracji społecznej rówieśników z zaburzeniami poznawczymi. Praca składa się z dwóch części. W pierwszej została omówiona kwestia zróżnicowania wiekowego osób po 60. r. ż. oraz zaburzeń poznawczych w kontekście demograficznego starzenia się Polaków. W drugiej części zostały zaprezentowane wyniki badań empirycznych przeprowadzonych wśród seniorów wspierających osoby w wieku podeszłym z zaburzeniami poznawczymi, których celem było uzyskanie informacji nt. motywacji, zakresu oraz częstotliwości udzielanego wsparcia i poczucia kompetencji pomocowych seniorów wspierających osoby starsze z zaburzeniami poznawczymi.

Metody i materiały. Pierwsza część artykułu została oparta o analizę teoretyczną publikacji naukowych z zakresu gerontologii społecznej. W części badawczej zastosowano analizę badań jakościowych z wykorzystaniem techniki indywidualnego wywiadu pogłębionego (IDI).

Wyniki i wnioski. Powszechny proces starzenia się społeczeństwa i wzrost liczby osób starszych z zaburzeniami poznawczymi sprawia, że zapewnienie im odpowiedniego wsparcia aktywizacyjno-opiekuńczego staje się jednym z głównych wyzwań dla polskiej polityki społecznej. Z procesem starzenia się społeczeństwa jest związana również kwe-

stia zapewnienia odpowiednich form aktywizacyjnych dla seniorów (zwłaszcza w początkowej fazie starzenia się). Analizując literaturę naukową z zakresu gerontologii społecznej oraz wykonane badania własne, wnioskujemy, że należy podejmować działania zachęcające seniorów do wspierania i aktywizowania swoich rówieśników z zaburzeniami poznawczymi poprzez prowadzenie działań informacyjnych, edukacyjnych oraz bezpłatnych szkoleń zwiększających wiedzę i kompetencje seniora wspierającego osoby starsze.

Słowa kłuczowe: starość, zróżnicowanie wiekowe osób starszych, zaburzenia poznawcze, wsparcie społeczne, senior dawcą wsparcia.

Age diversity of the elderly

Ageing is a dynamic, natural, long-term, and irreversible physiological process in the body. Old age is the final stage of ageing. People often talk about early and late old age, with the cut-off point being 75. The World Health Organisation (WHO) has adopted 60 as the conventional cut-off point for old age while distinguishing three sub-periods: old age (early old age) – from 60 to 74 years; old age (late old age) – from 75 to 90 years; and very old age (longevity) – over 90 years (Zych, 2001; Kraus, 1998; Kocemba, 2000; Kędzior, 2006).

Older people are diverse in terms of health, physical and mental fitness, and their life, social and economic situation. While in early old age, most people retain considerable physical and psychological fitness and social and economic independence, this changes in late old age. The functional capacity of older people varies depending on their age, hence the following groups have been distinguished in the senior citizen group: the *young old* – fully independent, psychophysically fit (60/65–74 years old), *the old* – requiring support in performing some daily activities (75–84 years old) and *the oldest old* – often requiring constant assistance in performing most of their daily activities (over 85 years old) (Fabiś, Wawrzyniak, & Chabior, 2015).

Cognitive disorders in the context of the demographic ageing of Poles

Today, we no longer question whether society is demographically old. According to the Rosset measure, the share of people aged 60 and over at 12% of the total population is considered to exceed the threshold of demographic ageing. According to this indicator, there are no societies in the world today that can be called "young" (Fabiś, Wawrzyniak, Chabior, 2015). In 2022, researchers observed a continuation of the ageing process of the population in Poland. At the end of 2022, the number of people aged 60 and over was 9.8 million, an increase of 0.7% compared to the previous year. The proportion of older people in the Polish population reached 25.9%, which indicates an increase of 0.2 percentage points compared to the previous year. The old-age dependency ratio increased by 1 percentage point compared to 2021. The ratio of the post-working age population per 100 working-age people was 39, while a year earlier it was 38.1. In 2022, the most numerous group of seniors were people aged 65–69 (25.7%). In previous years, the youngest age group, i.e. people aged 60–64, dominated. The least numerous group was still made up of people aged 80–84 and 85 and over (8.2% each). The distribution of the other age groups is similar, with 24.9% for 60-64-year-olds, 21% for 70-74-year-olds and 12% for 75-79-year-olds (Central Statistical Office, 2023).

The demographic ageing of the population is causing serious problems; as the years go by and physical and mental abilities decline, the risk of neurocognitive disorders increases in older people. Lost in everyday life, exposed to mood swings, disoriented, and misunderstood by those around them, they require constant care, initially from the closest family members. As the stages of the disease progress, carers decide to seek support from people outside the family circle, including both friends as well as professional help, which relieves them of their care responsibilities and enables young old people to pursue their professional activities or gives older old people a break (Ziomek-Michalak, 2022, 2023). According to the PolSenior 2 study, it is estimated that 16.8% of people over 60 show mild cognitive impairment and 15.8% are suspected of having dementia. The suspicion of dementia increases with the age of the elderly – from 12.2% in the first phase of old age to over 50% in the last phase (Błędowski et al., 2021).

Because of the above analyses, we can expect a significant increase in the number of people with cognitive impairments. According to the demographic forecast, a steady increase in the number of senior citizens is expected in the period up to 2060. In 2060, 11.9 million older people are expected to live in Poland, which is 21% more than in 2022. The senior citizen group will account for 38.3% of the total population. In 2060, all age groups will have increased in size compared to 2022. The largest increase will be in the oldest age group, i.e., those aged 85 and over. It is predicted that the size of this group will more than double compared to 2022. Demographers predict that the proportion of the three youngest age groups in the elderly population will decrease during this period. People aged 60 to 64 will make up only 15.1% of senior citizens (9.8 percentage points less than in 2022), the proportion of people aged 65 to 69 will decrease by 8.4 percentage points and will reach 17.3% in 2060, while the number of people aged 70–74 will decrease by 2.4% to 18.6%. The highest increase (by 7.5%) will be in the oldest age group – people aged 85 and over (Central Statistical Office, 2023). As a consequence of the further demographic ageing of Poles,

changes in the age structure of senior citizens and the prospect of deinstitutionalisation, there is an increasing need to engage and train informal carers to support elderly people with cognitive impairments.

Life expectancy and quality of life of people with cognitive impairment

As people get older, the frequency of neurocognitive disorders increases, which means that age is a significant risk factor for their occurrence (Ziomek-Michalak, 2023). Various *cognitive disorders* (in the areas of perception, attention, memory, and thinking) reduce the quality of life. Cognitive performance is an important element of everyday human functioning and is linked to quality of life. It allows us to explore our surroundings, form a picture of them, experience them and function effectively in them. Cognitive impairments cause a decline in the quality of life - cognitive functions are reduced, and neurodegenerative diseases (e.g., dementia or Alzheimer's disease) appear (Sumińska, Grodecka, 2022). Good cognitive condition, together with good health and social condition, determines successful ageing (Rowe, Kahn, 1997). Changes in the cognitive functioning of older people extend along a continuum, from normative ageing to dementia (Byczewska-Konieczny, 2017). The less functionally independent a person becomes, the more often they require care and support in their environment, becoming dependent on others, and thus their sense of quality of life decreases. With the development of cognitive disorders, many unfavourable changes occur in the patient's body, which makes it difficult, and in the advanced stage even impossible, to function independently without constant help from a carer (Korycki, 2021, 2023).

A study by the Central Statistical Office (2016) revealed that one-third of people aged 65+ have difficulty performing self-care activities (this includes dressing and undressing, bathing, getting in and out of bed or a chair, eating meals, using the toilet). The risk of being unable to perform these activities independently increases with age and is higher among the oldest seniors. The range of support needs is much broader when it comes to more complex activities (shopping, preparing meals, light and heavy housework, taking medication, using the telephone, and assistance with administrative and financial matters).

Support for elderly people with cognitive impairments

Social support is defined as "[...] a type of social interaction that is initiated by one or both participants in a problematic, difficult, stressful or critical situation" (Sek, 2001, pp.

16–17). A distinction is made between emotional, informational (cognitive), instrumental, material (tangible) and spiritual support (Kawula, 1996). Close relationships with others and the awareness of potential help in difficult situations protect the sick from feelings of alienation, strengthen their mental resilience, and become an existing resource that fulfils the function of primary prevention (Kawula, 1996; Sęk, 2001; Ziomek-Michalak, 2016). Family members – their children, grandchildren, and spouses – are the primary source of support for the elderly, with professional carers or care institutions being less common (Central Statistical Office, 2016; Ziomek-Michalak, 2016).

Among the general objectives of social support for the elderly, Barbara Szatur-Jaworska and Piotr Błędowski (2017, p. 12) mention the following in particular:

- [...] care, assistance with everyday activities, health-maintaining services, protection against violence and abuse), social (benefits ensuring an adequate level of consumption), and social (ensuring social participation);
- keeping older people active and autonomous for as long as possible;
- strengthening informal social ties that form a support network and replacing them with formal support when needed;
- keeping older people in their current living environment for as long as possible, if they so wish;
- shaping the living environment in such a way that it is age-friendly.

In the first phase of cognitive impairment, the senior needs support in dealing with official matters, shopping, taking care of clean clothes and moving around outside the home. In the second stage, the patient requires help and support from a carer in most activities of daily living, although they can move around their own home independently, understand simple instructions and perform self-care activities. In the third stage of the disorder, the patient needs constant help and support from a carer, mainly in the form of care and security, due to the impairment of independent functioning and uncontrolled behaviour (Korycki, 2023).

Senior as support

It is not uncommon for younger seniors to support and care for older seniors (spouses, parents, and neighbours). Civilisational and social changes are leading to changes in family care. Bearing in mind its feminisation, we can see that it does not always fulfil the comprehensive security of the needs of elderly people suffering from cognitive disorders. These shortcomings are due to the complex socio-demographic situation of the middle generation (40-60 years old), defined by sociologists as the *sandwich generation*, which looks after and supports its children and at the same time helps

its parents, fulfilling the obligation to care for, look after, support and secure many other needs. Sometimes, we deal with the phenomenon of parentification, when taking on the role of a carer for one's parent involves extensive activities, including feeding, shopping, cleaning, administering medication, accompanying them to doctor's appointments, doing housework, providing entertainment, helping with official matters, providing company, etc. Caring for the oldest members of society can lead to family impoverishment, conflict, violence, moral and economic weakness, and burnout. Due to the activities undertaken by the adult generation, there is an increasing trend towards the defamilialisation of care, i.e., its transfer to informal carers (Wawrzyniak, 2017).

Looking at demographic changes, we can see that the challenge is to utilise the potential and experience of younger older people in caring for those with cognitive impairments. Involving senior citizens in care activities and social activities is a way to maintain good psychophysical conditions and to help the elderly live independently; it is an antidote to loneliness and passivity. Older people represent a potential that should be utilised by non-governmental organisations and local communities. They are, above all, a source of knowledge and experience, as well as practical skills useful to others. The time that seniors can devote to working in the local community or various organisations is particularly valuable (Babiarz, Garbuzik, 2017).

The caring activities of senior citizens are in line with the theories of positive ageing. For example, in the typology of attitudes towards one's old age, Suzanne Reichard (Bromley, 1969) points to the attitude of integration and adaptation, which is characterised by kindness and a willingness to help others, and to participate in the life of the wider community. Referring to the functioning styles of older people in Olga Czerniawska's classification (1998), we can see that the social style is characterised by people who devote their free time to working for others and the social environment. Being active has an impact on all areas of human functioning – biological, psychological and social. Being active can help maintain long-term fitness in each of these areas. Involving senior citizens in the organisation of support for elderly people with cognitive impairments will contribute to increasing their participation in the social activities of senior citizens and will counteract their marginalisation, alienation, as well as lone liness and isolation. It may consequently contribute to changing the image of old age (Bakalarczyk, 2023).

Analysis of our own research

The main objective of the study was to obtain information on the motivation, scope and frequency of the support provided and the sense of helping competence of seniors supporting elderly people with cognitive impairments. To obtain information on the above issues, a qualitative study was conducted using the individual in-depth interview (IDI) technique,

which is a classic example of a qualitative method. The sample size for an individual in-depth interview should be between 15 and 100 people selected for scientific research (Młyniec, 2002). This technique was chosen, among other things, due to the age of the participants, the scope, purpose and course of the research (conducted in a fairly free manner, allowing seniors to express themselves fully, but focusing on the purpose of the interview and research questions, and on so-called follow-up questions, i.e., the ongoing supplementation of the interview with further, in-depth questions). The interviews were conducted in December 2023. 22 senior citizens over the age of 60 took part in the study. During the 9th Senior Educational Congress on cognitive disorders, which took place in October (organised by the Hej, Koniku! Foundation for Helping Young People and Children with Disabilities), they declared in an information survey that they regularly support elderly people (over 60 years of age) with cognitive impairments. The respondents included 18 women and 4 men, including 8 people aged 60–65 (7 women and 1 man), 12 people aged 65–70 (10 women and 2 men) and 2 women aged 70–75. All respondents stated that they supported one person. Both the respondents and the seniors they supported lived in the capital city of Warsaw. Seventeen of the participants supported their family members (including 13 close and 4 distant family members), and 5 supported unrelated people (including 3 acquaintances and 2 strangers). Eighteen of the older people support seniors with cognitive impairments living with their families, and four support seniors living in 24-hour care facilities. The interview participants were informed about the purpose of the interview and participated voluntarily. The interviews lasted two hours on average (between one and a half and over two hours) and were conducted in person at the Hey, Koniku! Foundation for Helping Young People and Children with Disabilities.

The main research questions concerned the volunteers' motivation to support senior citizens with cognitive impairments, and the scope, frequency and form of the support they provide (including whether it varies depending on the place of residence of the person with cognitive impairments). The research tool was an original interview question-naire consisting of seven research questions concerning:

- frequency of support provided and motivation to support seniors with cognitive impairments;
- scope of support provided;
- cooperation with the family (institution where the sick person is staying);
- sense of competence in supporting people with dementia (including participation in training, how knowledge is passed on by the family);
- role changes and forms of support as cognitive impairment progresses;
- willingness to continue supporting people with dementia (including after the death of the person currently being supported);

 ways to encourage other older people to get involved in supporting peers with cognitive impairment.

Of the 22 respondents, 13 have been supporting seniors with cognitive impairments for more than two years, eight for more than a year and one for nine months. The majority of the participants (16 people) support people with cognitive impairments twice a week, four support them once a week and two support them more than twice a week. The average duration of a meeting is four hours. The main motivations for the respondents to support seniors with cognitive impairments are:

- attachment to the sick person, long-standing acquaintance, being a family member or close friend;
- willingness to help other people and to give something back for the support received;
- willingness to use up free time, which is in surplus after retirement and/or raising grandchildren;
- willingness to feel needed and to support the family of the senior with cognitive impairment in activating and caring for the sick person;
- being guided by religious values and ethical principles encouraging support for people in need of help;
- a "sense of duty to help others" and the hope that by supporting others, they will also receive support in the future;
- opportunity to gain new experiences, including knowledge of cognitive disorders and skills in caring for seniors with cognitive disorders, which they will be able to use in the future to support other sick (dementia) family members (including spouses) and pass on their knowledge to those in need;
- willingness to spend time with other people, both seniors with neurodegenerative disorders and their relatives and supporting medical staff;
- willingness to improve the quality of life of seniors with disorders who, in the opinion of their carers, "did not deserve their illness" and the related social exclusion of the sick person and their family carers.

The degree of support varied depending on the severity of the cognitive impairment and the place of residence (with family or in an institution, in the case of respondents' supported elderly relatives in a nursing home or hospice). The main areas of support provided by respondents to seniors with mild neurodegenerative disorders (according to the *Krótka Skala Oceny Stanu Psychicznego MMSE* [Mini-Mental State Examination, MMSE]) are:

 supporting senior citizens in preparing themselves and going out for a walk together, as well as visiting cultural institutions and places of worship;

- motivating and supporting an elderly person who is ill to get out of the house and interact with peers, including both going out to clubs and senior citizen groups and organising meetings at the home of a senior citizen with cognitive impairments, in which the senior citizen's existing friends participate;
- motivating and supporting them to go to sports and leisure facilities together, including the outdoor gym;
- helping the sick person to prepare a list of small purchases and going to the nearby shop together;
- spending free time together at home/in the flat, especially solving crossword puzzles and playing board games;
- taking care of the sick person when their family carers are out.

The main areas of support for seniors with moderate to severe cognitive impairments include:

- helping the sick person choose weather-appropriate clothing, get dressed and go out onto the terrace, balcony or for a short walk;
- motivating the seniors with dementia and doing exercises together to develop fine motor skills and train memory;
- being a "link" between the senior and their social environment, including both passing on messages and reading letters from friends, as well as coming to the sick person with their existing friends and spending free time together;
- helping with meals and drinks;
- supporting the sick person in hygiene activities;
- looking at photos and memorabilia together and having conversations about memories.

To provide full-time care, full board and constant staff (including hygiene, feeding, transport to and from the doctor, etc.) to seniors in institutions, the caregivers mainly focus on ensuring that the patient spends their free time actively, including preparing for and going for walks, chatting, reading the press and books together, looking at photos and family memorabilia, and ensuring that the sick person has contact with their existing social environment, especially with friends.

The vast majority of participants (16 out of 18 people) positively assessed the cooperation with the family of the sick person and the institution where the supported senior resides (3 out of 4 people). As the study participants emphasised, the immediate family (caring for the senior) is grateful to them for maintaining contact with the senior and supporting them in caring for them. Most carers also positively assess the cooperation with the institution where the senior lives, emphasising the institution's openness (in setting visiting hours or to carers' ideas) and (when necessary) the support of the institution's staff, mainly psychologists, for the carers.

Respondents mentioned the following difficulties in their cooperation with families: families being too demanding and trying to put pressure on support providers to provide more and more support; difficulties in maintaining relationships – the family crossing previously established boundaries and treating senior carers as immediate family members (which makes them feel embarrassed) and problems in communicating with the family, including difficulties in getting through, arranging visiting times, etc. The main difficulty that the survey participants indicate in their cooperation with the institutions is the bureaucratisation of contacts, including setting and observing visiting times and making entries in the entry and exit books.

The participating seniors emphasised that they did not have any expertise in supporting people with cognitive impairments and that they provided support based on empathy and their "own conviction that this is what the person with dementia needs." However, the majority (18) obtained basic information about cognitive impairment and how to respond to the behaviour of the person with dementia from the person's caregivers. In addition, half of the study participants (11 people) regularly search for information about cognitive impairment and the principles and forms of support for the person with dementia on the Internet and in scientific literature. At the same time, the respondents emphasised the lack of free training and professional literature in this area (written in "accessible language"). The survey participants also emphasised the insufficient knowledge of social assistance and integration workers (especially OPS), who in many cases are unable to adequately support family carers and volunteers in caring for seniors with cognitive impairments. The problem of insufficient knowledge of local government employees (postmen, cultural workers, etc.) about cognitive disorders and ways of communicating with seniors with dementia is also (according to the respondents) a big problem when dealing with sick people in offices, hospitals and during visits to cultural, sports and recreational institutions.

The role and tasks of seniors supporting elderly people with cognitive impairments are adapted to the state of health and development of neurodegenerative disorders (and other accompanying conditions) in the supported persons. In the initial stages of cognitive impairment, support is focused on activities aimed at maintaining fitness and slowing down its progression. As the dementia progresses, the support person moves from an activating role to a supporting role to a caring role, helping the patient with their daily functioning, including supporting the family in their caring role.

All participants in the study declared their continued willingness to support seniors with cognitive impairments; at the same time, the majority of them (18 people) emphasised during the interview that this would also depend on their state of health and the state of health of the sick person, including the feeling of being able to continue supporting them. Even though the vast majority of seniors (20 out of 22 people) support people with cognitive impairments, among other things for family reasons and a sense of social ties, 19 seniors still intend to support another person with cognitive impairment from their local community or a 24-hour care facility after the death of the supported person, as they declared.

The main activities that respondents believe could increase the number of seniors (especially in the so-called first phase of old age) involved in supporting elderly people with cognitive impairments should include:

- widespread information activities on cognitive disorders, e.g. in the form of media campaigns, weaving the theme of people with cognitive disorders into popular TV series or organising information meetings (e.g., in senior citizens' circles and clubs);
- widespread educational activities concerning cognitive disorders and counteracting the social exclusion of people and families of people with neurodegenerative disorders, so that they can fully participate in social life, are not ashamed to ask for help and are open to people who want to support them in caring for a sick family member;
- organisation of free, profiled training courses showing how seniors can support other elderly people with dementia;
- increased activities of non-governmental organisations and other social institutions (e.g., the Association of Pensioners and Disabled Persons) showing seniors how volunteering can be a way of spending free time actively.

Conclusion

The widespread ageing of the Polish population and the increase in the number of seniors with cognitive impairments pose significant challenges for social policy, not only in terms of preparing qualified staff with developed social competencies but also informal carers for senior citizens with advanced cognitive impairments, who require assistance with the most basic everyday activities (toilet, hygiene, getting dressed, eating). It seems necessary to involve non-governmental organisations and the youngest, active, healthy seniors aged 60–74, for whom supporting seniors with cognitive impairments can be a form of leisure time management, motivation for further activity and a sense of being needed. As our research suggests, to increase the number of senior citizens involved in supporting elderly people with cognitive impairments, general educational and information activities on cognitive impairments, methods and forms of supporting people with dementia and their family carers, and promoting volunteering as a form of involvement for the elderly, are necessary. Funding training courses to improve

the knowledge and skills of carers supporting elderly people with dementia and their volunteers is also important due to the need to organise care and create space for building a support and information network. These activities can contribute to the implementation of respite policy for family carers (Basińska, 2013).

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